

Proclamation

by

Steven L. Beshear
Governor

of the

Commonwealth of Kentucky



To All To Whom These Presents Shall Come:

- WHEREAS, There are nearly 7,000 diseases and conditions considered rare (each affecting fewer than 200,000 Americans) in the United States; and
- WHEREAS, While each of these diseases may affect small numbers of people, rare diseases as a group affect almost 30 million Americans; and
- WHEREAS, Many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected; and
- WHEREAS, While approximately 340 orphan drugs and biologics have been approved for the treatment of rare diseases affecting between 11 and 14 million people according to the Food and Drug Administration, that leaves well over 15 million Americans with rare diseases who have no treatment specific to their disease; and
- WHEREAS, Individuals and families affected by rare diseases often experience problems such as a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options, and problems related to accessing or being reimbursed for treatment; and
- WHEREAS, Some rare diseases, such as Lou Gehrig's Disease, are relatively well known. Many others, such as Erdheim-Chester Disease, are not known at all by the public so that patients and their families must bear a large share of the burden; i.e., raising funds for research; and
- WHEREAS, Thousands of residents of Kentucky are among those affected by rare diseases since nearly one in ten Americans have rare diseases; and
- WHEREAS, The National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on February 28, 2010, and patients, medical professionals, researchers, government officials, and companies developing treatments for rare diseases are joining together to focus attention on rare diseases as a public health issue on that day;

NOW, THEREFORE, I, STEVEN L. BESHEAR, Governor of the Commonwealth of Kentucky, do hereby proclaim February 28, 2010, as

RARE DISEASE DAY

in Kentucky.

DONE AT THE CAPITOL, in the City of Frankfort this 27th day of January, in the year of Our Lord Two Thousand Ten and in the 718th year of the Commonwealth.

A handwritten signature in black ink, appearing to read "Steve Beshear", written over a horizontal line.

STEVEN L. BESHEAR
GOVERNOR

A handwritten signature in black ink, appearing to read "Trey Grayson", written over a horizontal line.

Trey Grayson
Secretary of State

RECEIVED AND FILED

DATE 1/28/10

TREY GRAYSON

SECRETARY OF STATE

COMMONWEALTH OF KENTUCKY

BY R. J. Miller
